# Adult Social Care and Unmet Needs

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*Report commissioned and funded by Access Social Care*

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Cover image by Matthias Zomer

# Foreword

"*The object of welfare policy is to meet human need*" Taylor-Gooby (1991:171)

The UK social care system, which in its current form dates largely from the post-Second World War welfare state settlement, has both expanded hugely in recent decades, and by common consent is now dysfunctional in various respects. It is not without irony that Thorlby *et al*., (2018:3) pointed out that, whilst the 70th anniversary of the NHS was marked with much celebration, the same anniversary of social care passed largely unnoticed. The fault line established 70 years ago between health care which is provided by a national agency and free at the point of use and social care which is means-tested and provided by local government, remains a fundamental source of inequity and unfairness today.

These issues include the level of national funding and how that is determined, the allocation and availability of funding among social care authorities, the individual budget decisions and choices made by those authorities and the way decisions on funding and care packages are taken for individuals with social care needs. Two very important questions that arise from this dysfunctional system, are the extent to which the rights of individuals, for example under the Care Act 2014, are being respected and, if not, what is the level and urgency of tackling those unmet needs.

This report considers the academic and other material which has been produced in recent times to address these and related questions. It has been validated by the experience of the authors and contact with active professionals in the field, but is in essence a literature review. Further empirical work would be able to address in detail the problems in the national and local funding systems and the levels and types of unmet need, and consider the proposals which are being put forward currently to remedy these issues and identify those which have the greatest chance of success in terms of helping individuals in need.

This report was commissioned by Access Social Care with the following aim and objective in mind:

**Aim**

The overall aim of this review was to present a picture of levels of unmet need in relation to social care in England since 2008 to the present, so as to encapsulate austerity measures and the Care Act 2014.

**Objective**

The objective was to bring together academic analysis to gain a better understanding of unmet need, with a view to informing better decision making.

In order to allow the report to be accessible to a wide audience, we have provided commentary on the facts throughout the report.

## Access Social Care

Access Social Care is a new independent legal charity providing access to justice for people with social care needs. Access is a central hub for social care education and advice, helping individuals to understand and secure their lawful right to social care. By motivating organisations to collaborate to drive culture change on the frontline of social care and to share data on unlawful decision making Access Social Care strives to achieve systems change at all levels of social care decision making.

## Executive Summary

When the nation clapped for carers on a Thursday evening during the first stage of the COVID-19 pandemic, there was some acknowledgment that it was not just the staff of the NHS who were being recognised. But this was a rare instance when the thousands of people providing essential social care around the country were afforded the same standing as doctors and nurses. Social care has long been the Cinderella to the NHS's Prince Charming. While the NHS has continued to receive considerable spending increases even during austerity, social care which is largely provided by local government, has seen its resources falling even as demand increased significantly. As we begin to contemplate what the country should look like after COVID-19, it is an opportune moment to remind ourselves that those who need social care all too often are not being helped and supported. Needs are not being met. This scoping report starts to examine that level of unmet needs, the scale of the challenge in different forms (age, disability and so on) and begins the work of considering what better approaches could create a social care system which is fit for the 21st century.

**Main findings**

- The number of people with a disability in the U.K. has continued to rise in recent years, and is now around 21% of the total population, or 14.1 million people
- There is also an increasing number of people with learning disabilities who thanks to medical advances are now not only surviving childhood but living much longer. Their needs will call for particular attention in coming years.
- The number of older, and oldest-old, people is also rising as it is in many countries. Currently there are over 703 million people over the age of 65 Between 2015 and 2030 there will be some 500 million more people over 60 in the world. In the U.K. the number of people over 85, when needs tend to increase sharply, will double from 1.6 million by 2041.
- These changes and pressures on adult social care however have not been matched in the last decade by increases in available resources or by clearly articulated and robustly modelled strategies for tackling these incipient challenges. Since 2010 the amount spent by councils first fell sharply and has since recovered slowly to near the same real times level, but during a decade

when demand and needs have risen considerably. There is a broad consensus across local authorities of all political stripes that social care is underfunded.

- The numbers of people receiving social care has fallen by 7% between 2015/16 and 2018/19.
- Unsurprisingly then, many studies identify large and increasing numbers of people who are not receiving the social care they need and to which they may well be entitled under the legislation.
- There is, though a dearth of studies that specifically look at unmet needs – especially for people from BAME backgrounds and LGBT groups.
- 'Need' and 'unmet' need remain conceptually complex, with functional-based approaches to measure it remaining the default. More qualitative accounts of what unmet need means for the everyday lives of people with disabilities are missing.
- Although actions are often discussed to remedy some of these identified problems there is no current plan or timetable for doing so.

**Recommendations.**

1. Immediate action is needed to address underfunding of social care especially given the increased pressures COVID-19 has placed on the system.

2. A full and empirically sound picture of the levels and types of unmet need for social care.

3. On that basis a better and shared understanding of the resources which would be needed over time to move towards meeting those needs.

4. Analysis of the impacts of those resource implications for local government and the extent to which that is viable in the current system given their other responsibilities.

## Acknowledgements

The authors would like to thank Access Social Care for commissioning and funding this study, and for the work that they do to help secure people's legal right for support to meet their social care needs. We would also like to thank all those who gave up their time to talk to us about the issues we discuss in this report.

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## Terminology

**Disability:** We use the Equality Act 2010 definition of disability: [1] *A person is considered to have a disability if they have a physical or mental impairment that has 'substantial' and 'long term' negative effects on their ability to do normal daily activities* (also see DWP, 2020).

**Adult social care:** We use the generally accepted and broad definition that refers to care and support for people who, due to their disability, age or long-term illness need help with every-day living such as getting up in the norming, dressing, eating and washing as well as engaging in meaningful paid or unpaid activities and socially interacting with others. Social care can be provided in people's homes, or within supported housing, residential or nursing homes.

**Informal care:** This refers to care and support provided by friends, family or neighbours. It is usually unpaid.

**Formal care or state care:** This refers to care and support provided by paid local authority (LA) or private care providers.

[1] https://www.gov.uk/definition-of-disability-under-equality-act-2010

## Introduction to the Current Funding Model

The current public funding system does not attempt to be prescriptive about whether the element identified in the funding to a council for social care is actually spent on social care. The funding for councils is provided through a number of sources, which have been changing rapidly in recent years. Very importantly, the balance of different sources between councils also varies considerably. This also has a significant impact on the funding that is translated into social care spending. Council tax nationally provides around 50% of Council budgets, with 30% from government grants and 20% from business rates. Since 2010 government grants have fallen sharply by around 38% or over £12 billion. The amount raised from council tax has increased slightly and the amount from business rates has also risen. But local government spending has fallen altogether from around £60 billion to around £50 billion.

However these national figures conceal very different impacts on different councils in different areas. This is because councils have different tax bases in terms of the value of housing in their area, and historically very diverse balances between the proportion of their budget raised from council tax and from government grants. For example, the spending power of councils in deprived areas has fallen by twice the level of councils in more affluent areas. This has meant that the relative impacts on councils' ability to fund social care have been very different, despite the fact that individuals in the different areas have the same rights under the Care Act 2014.

Government grant-funding to councils is constructed on the basis of a number of formula-based calculations. These make some effort to reflect the specific conditions in each area or council, but operating at a national level as they do, they are fairly general and inevitably cannot get far below the surface of a council area's broad characteristics. So the calculations cover population, in broad terms and relative deprivation, but also the rural nature of an area which can impact on the provision of services, and what is called area cost adjustment, essentially reflecting higher costs in the south than in the north.

The extent to which these different aspects are emphasised in the grant settlement is itself a political choice which changes over time. So, for instance, a Labour Minister might give more weight to derivation since deprived areas are more likely to have elected a Labour council. A Conservative Minister might give more stress to the higher costs of southern and rural areas which tend to elect Conservative councils. Although these are legitimate political choices by an elected government, they would further stretch the already tenuous connection between grant levels and the need, for example on social care, in a given council.

Importantly, the grant settlement does not directly reflect an assessment of how far individuals in a council area who would be liable to pay for some or all of their social care under the eligibility rules. Although this might be broadly reflected in the criterion of deprivation, it is a further indication of the extent to which there is little correlation between social care need and the funding available to fund it in an area.

For the financial year 2016/17, the government introduced the social care precept. Under this, councils could increase the rate of council tax in their area by 2%, with the money raised going to support adult social care. This provided some welcome additional funding. However, the rules on the precept are fairly loose, and councils only really have to make the case that the precept was providing money which would otherwise not have been added to the social care budget. It does not have to maintain the original budget at the previous year's level. So, if it was apparently planning a cut of the equivalent sum, the actual budget for social care might not change from year to year.

The rights individuals have to receive social care were redefined and restated in the Care Act 2014, which was a significant step forward in several respects. It removed the local variations which had previously always existed in terms of eligibility criteria and the right to have an assessment of needs. But this progressive step was not matched by any resolution of the many other factors which determine whether the care to which someone is entitled is actually provided.

## Evidence from the Literature

In 2009, the [2]UK ratified the UN Convention on the Rights of Persons with Disabilities. In so doing, the country agreed to eliminate disability discrimination, enable disabled people to live independently in the community, ensure an inclusive education system and protect disabled people from harm. These rights were also reflected in the Equality Act 2010 in terms of direct and indirect discrimination and in the Public Sector Equality Duty which naturally applies to central and local government.

*Prevalence of people with disabilities*

People with disabilities constitute a significant proportion (a billion people [15%]) of the world's population ([3]World Health Organisation [WHO], 2020). Figures published by the DWP (2020:7) from the [4]Family Resources Survey (FRS) show that in 2018/19, there were 14.1 million people (1 in 5 or 19% of the total UK population) who reported having a disability (an overall increase from 11.3 million (19%) in 2008/09). Of this total, 44% were of pension age, 19% were of working age and 8% were children. In the last decade, there has been a rise in the number of people with a disability who are working age, from 14% to 19%; a 6% to 8% rise in children; and a 47% to 43% decrease in pension age adults (65+) with a disability [5](DWP, 2020:7).

*Regional variations*

Regional variations exist across the UK. FRS figures (DWP, 2020:7) show that the percentage of people reporting a disability in Wales (25% or 0.8 million), Scotland (24% or 1.3 million), and Northern Ireland (23% or 0.4 million) are all higher than in England (21% or 11.6 million). In 2018/19, the highest proportion (28% or 0.7 million)

[2] United Nations Treaty 2006 Chapter IV Human Rights 15. Convention on the Rights of Persons with Disabilities, United Nations Treaty Collection [online] https://treaties.un.org/doc/Publication/MTDSG/Volume%20I/Chapter%20IV/IV-15.en.pdf [online] [Accessed 22/09/20]
[3]World Health Organisation 2020 [online] https://www.who.int/health-topics/disability#tab=tab_1 [Accessed 20/09/20]
[4] Family Resources Survey 2018/19 Department for Work and Pensions 2020 [online] https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/874507/family-resources-survey-2018-19.pdf [Accessed 18/09/20]
[5] Family Resources Survey 2018/19 Department for Work and Pensions 2020 [online] https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/874507/family-resources-survey-2018-19.pdf [Accessed 18/09/20]

of people in England reporting a disability were living in the North East, followed by the North West (25%; 1.8 million). Yorkshire and Humberside, and the West Midlands both had proportions of 24% (1.3 and 1.4 million respectively) followed by East Midlands (23% or 1.1 million) and the South West (23% or 1.3 million). The proportions of those reporting a disability are much lower in the East (20% or 1.2 million), the South East (19% or 1.7 million) and London, which has the lowest proportion (13% or 1.2 million) (see DWP 2020:7). DWP explain these regional variations as partly due to demographic differences; some specific regions have higher proportions of people of state pension age (65 yrs) who are twice as likely to report a disability compared to the overall population (see Table 4.4 in DWP 2020). What this tells us is that levels of disability are not equally distributed across regions. This impacts on levels of need and the ability of regional local authorities (LAs) to address unmet need with requisite funding.

*Breakdown of disability by category*

The FRS data use a standard list of impairments' when calculating breakdown figures of disability including mobility, stamina/breathing/fatigue, dexterity, mental health, memory, hearing, vision, learning, social/behavioural and other (see Table 4.6 in DWP 2020). Of the sample of respondents of working age (*n*=5,024) for 2018/19, nearly 40 per cent (39%) reported having a mental health impairment (an increase from 36% in 2016/17) compared to 9% of the sample of state pension age (*n*=4,135). As regards a learning disability the percentages were 14 for those of working-age compared to 8 of those of state pension age. Regarding social/behavioural impairment, the proportions were 9% and 16% respectively.

Improved medical and health care has meant that more people in the UK live longer, and all regions of England have an ageing population, with the numbers of people aged 65+ growing considerably faster than younger age groups which are by and large decreasing. Partly as a result of the second wave of baby boomers (those born in the 1960s) living longer into their 70s and 80s, the Office for National Statistics (2018)

states that [6]*'In 50 years' time, there is projected to be an additional 8.2 million people aged 65 years and over in the UK – a population roughly the size of present-day London'.* The population most likely to need health and social care services (those aged 85+) is projected to increase dramatically from 1.4 to 2.7 million from 2017 to 2040. They are also more likely to be concentrated in rural and coastal areas where social care infrastructures including transport and availability of care staff are often not as robust compared with urban areas. For example, the 2011 census indicated that the old-age ratio in the New Forest (county of Hampshire) is 42.7 (compared to the overall UK ratio of 27.5) and the total dependency ratio is 70.7(compared to the overall UK ratio of 55.1). [7]Estimations of population by age in the New Forest give a total figure of 52,800 people aged 65 or over in 2019 of which 9,900 (19%) were over 75 and 3,500 (7%) were over 90. These figures are expected to rise to a total of 64,300 people over 65 in 2030, 11,800 of whom will be 75 and over and 4,800 being 90 and over. [8]The New Forest has other challenges too, such as providing services in a largely rural area with a sparse population, a declining support-worker pool, and where affordable and accessible transport and housing are scarce.

The number of adults of working age with disabilities also reflects improvements in medical and health care. This includes people with a learning disability. Taking longevity for this category (around [9]2% of the total UK population) which includes Down's syndrome as an example, their life expectancy has increased from around 12 years in the late 1940s to 65 (women) and 66 (men) ([10]NHS Digital, 2019). Though overall, life expectancy for women and men remains younger than the mainstream population ([11]LeDeR 2019). Consequently, the number of people living in England

[6] Office for National Statistics https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/articles/overviewoftheukpopulation/august2019 [Accessed 21/09/20]

[7]2018 Projecting Older People Population Information System POPPI v11 April 2019 Institute of public care/Oxford Brookes University - Figures based on Census 2011. www.poppi.org.uk [Accessed 30/09/19]

[8] Paraphrased from Forrester-Jones (2020) Looming Crisis Forrester-Jones, R. (2019). Confronting a looming crisis: People with learning disabilities and/or autism and their carers getting older. https://www.bath.ac.uk/publications/report-confronting-a-looming-crisis/attachments/RFB_Report.pdf

[9] NHS Digital 2017-18 (collects and publishes data from across the health and social care system in England) estimates that around 2% of the population in England have a mild learning disability with 0.4% having severe or profound learning disabilities (NB: this figure is based on n=126,476 or 44.5% of the Quality of Outcomes Framework Learning Disability Register – which means that the data have not been extracted from all GP practices and so data coverage varies between CCGs). [Accessed 25/09/19]

[10] NHS Digital (published 24 January 2019) Health and Care of People with Learning Disabilities:2017-18 Summary Report https://files.digital.nhs.uk/BA/4F4C1D/health-care-learning-disabilities-1718-sum.pdf [Accessed 25/09/19]

[11] The Learning Disability Mortality Review (LeDeR) Programme Annual Report 2019. Figures taken from 1April 2017-31December 2018. https://www.bristol.ac.uk/media-library/sites/sps/leder/LeDeR_Annual_Report_2018%20published%20May%202019.pdf [Accessed 25/09/19]

with a learning disability who are aged 45+ is increasing - estimated to be [12]549,403 (53% of the total (1,043,196) learning disabled population in 2019), 5% (26,723) of which are aged 85 or over. These figures are predicted to rise to 605,646 people aged 45 and over (55% of the total number: 1,108,257), 6% (37,953) of which will be aged 85 and over by 2030. The predicted number of people with [13]Down's syndrome who are 45 and over is 9,379 in 2019, rising to 9,524 in 2030. Whilst this overall improvement is to be welcomed, structural movements in society including changes in gender roles, lower fertility rates, a rise in cohabitation and divorce, all mean that that the pool of informal care is decreasing, placing higher demands for formal social care provision and leading Turner and Bernard (2014:4) to estimate that by 2030, around 30% more adults with learning disabilities aged 50+ in England will require social care services with an estimated 164% increase in individuals over 80 needing social care.

[12] Projecting Adult Needs and Service Information (PANSI) (2018) based on Emerson and Hatton (2004) Estimating Future Need/Demand for Supports for Adults with Learning Disabilities in England. NB: these figures do not include Autistic Spectrum Conditions. www.pansi.org.uk [Accessed 30/09/19]

## Adult social care

How to care for adults with disabilities, and whose responsibility it is has been a social policy issue since the Elizabethan Poor Law of 1601. Yet Hall, Needham and Hamblin (2020:321) argue that 'adult social care' as a concept only really became distinctive in 2005 following the local government organizational split between children and adult services. Today, adult social care generally refers to a range of activities to support older people, or people with a disability or physical or mental illness to live independently and maintain their wellbeing and safety. Social care provision may be long-term i.e. support provided by a local authority (LA) following a formal needs assessment (and regular review) to a person to maintain their wellbeing or short term i.e. time-limited support (perhaps just one 'episode' (e.g. a few days support) following discharge from hospital). It can include 'personal care' (e.g. help with getting up in the morning, washing and dressing), as well as support to engage in meaningful activities and to help individuals socially interact with others.

*Who provides social care?*

Social care may be provided informally, by friends, family or neighbours (usually unpaid) or semi-informally (either paid or unpaid) through civil society, NGOs and charities, or formally by (usually paid) LA or private care providers. It can be provided in people's homes (domiciliary care), or in day centres, or via reablement services to regain independence, or within supported housing, or residential and nursing homes, and can also include the provision of adaptations (including digital and other technologies) for people's homes.

***Comment:*** The variety of ways in which adult social care may be provided, and the mixed locations of care provision adds to the complexity of social care, especially in terms of organising and managing it.

## Social care funding

Our description illustrates the many decisions and considerations which are applied to the funding system. In particular the current structures mean that although an individual may well be able to access an assessment of their social care needs in accordance with the legislation under the Care Act 2014. However, the funding system which is then applied essentially has no correlation between the aggregated needs of individuals in a given area, and the resources which are provided to meet those needs. Until and unless this disjunction is tackled there will continue to be a serious, perhaps inevitable, risk of substantial unmet needs within the population.

Looking at changes over the last decade,[14]In 2018/19, LAs that had responsibility for the provision of social care (n=154) in England spent a [15]total of £22.2 billion on adult social care. This was made up of funds from their [16]central budget including money raised from the additional 'social care precept' added to the Council Tax charge (if they provided social care to adults), income from social care service-users, and income from the NHS).

Whilst the total expenditure in 2018/19 amounted to an increase of £800 million from the previous year, adjusting for inflation, the total amount spent on social care was £300 million below the level it was in 2010/11 with just under half spent on working-age adults, with the remainder spent on people aged 65+ (see King's Fund, 2019).

For older people (aged 65+) the majority of spending (66%) was directed to those who needed physical support, with the rest on cognition, learning disability, mental health and sensory conditions. For working-age adults (aged 18-64) the majority (70%) was spent on people with learning disabilities (King's Fund, 2019).

[14] The King's Fund (2019) Key facts and figures about adult social care [online] https://www.kingsfund.org.uk/audio-video/key-facts-figures-adult-social-care [Accessed 22/09/20]
[15] NB: total expenditure quoted here is defined differently to ADASS 2020 calculations.
[16] https://digital.nhs.uk/data-and-information/publications/statistical/adult-social-care-activity-and-finance-report

***Comments:*** we make several comments concerning these figures. Firstly, the shortfall in expenditure on social care over time may in part reflect advances and successes in health and social care for older people, spurred on by the government agenda for healthy ageing. Examples of strategies include coalition PM David Cameron's [17]Dementia Challenge, launched in 2015 and the subsequent [18]Challenge on dementia 2020: implementation plan (published in 2016) that helped develop over 100 dementia friendly communities; the fruits of this strategy 'may' have decreased the need for *some* social care over the intervening years. The new Ageing Society Grand Challenge which includes a UK Research and Innovation (UKRI) £98 million investment [19]Healthy Ageing Challenge Fund to develop markets for products and services that help maintain older people's independence and prevent transition into higher levels of care may also reduce the need for some social care, these strategies reflecting global healthy ageing frameworks (see [20]Beard et al., 2016).

Secondly there has been a long-term reduction in the funding of adult social care since 2006. This started with a reduction of one fifth of the £8 billion spent on older people (including a growing number of people with mild to moderate learning disabilities living into old age [Tuffrey-Wijne *et al.,* 2016]) by charging them for their care (see NHS 2006). This was followed by a suite of 'austerity' measures following the 'financial crisis' of 2008. Since 2010, in England, LAs have been pressed by falling revenues to make further adult social care budget savings year on year. By 2016, local councils had experienced five years of funding reduction which amounted to £4.5bn tracked by previous Budget Surveys. Unsurprisingly, the Association of Directors of Adult Social Services (ADASS) warned that they would need an extra £1.1bn to maintain levels of care provided in previous years. They also cautioned government that the quality of care they could provide was being compromised. 82% of Directors of Adult Social Care reported that more providers already faced quality challenges as a result of savings they were being forced to make ([21]ADASS Budget Survey 2016).

[17] https://www.gov.uk/government/news/pm-launches-next-phase-of-britains-fight-against-dementia [Accessed 22/09/20]
[18] https://www.gov.uk/government/publications/challenge-on-dementia-2020-implementation-plan [Accessed 22/09/20]
[19] https://www.ukri.org/innovation/industrial-strategy-challenge-fund/healthy-ageing/ [Accessed 22/09/20]

[21] https://www.adass.org.uk/media/5379/adass-budget-survey-report-2016.pdf [Accessed 22/09/20]

The 2017 ADASS Budget Report (p8) noted that pressures on care provision remained. This was due largely to: increasing longevity and numbers of people with complex and therefore costly support needs, the introduction of the National Living Wage driving up staff costs; and continuing funding reductions and consequential planned savings from adult social care budgets. These totaled £824m, bringing cumulative savings since 2010 to £6.3bn. Whilst the Spring Budget of 2017 included an additional £2bn for the period 2017/18 – 2019/20 as part of the Improved Better Care Fund (IBCF), this was reduced in 2018/19 to £674m and in 2019/20 to £337m (see 2018 ADASS Budget Report p8). The COVID-19 pandemic has only exacerbated this depleted funding trajectory, The [22]ADASS Budget Survey 2020 para 2.1 p8 reporting that:

[23]*"budgeted' spend by councils on adult social care rose from £14.8 billion in 2018/19 to £15.1 billion in 2019/20. Actual spend in 2019/20 was £15.3 billion, some £197 million over budget. Councils have budgeted to spend £15.7 billion in the year 2020/21. The proportion of councils' overall budgets being spent on adult social care has remained constant since 2017/18, at around 37% of all spending. A quarter of councils plan to use non-recurrent funding, for example council reserves, to fund their base adult social care budgets for 2020/21."*

Essentially, councils continue to face the ever-widening gap between the requirements of its various populations who have rights and needs regarding social care, and financial resources which do not keep pace with the rising costs, rising demand, and rising complexity of social care demands. There is only so much that can be done to reduce spending on other statutory services such as roads and children's social care, or by further efficiency measures.

Third, since 2010/11, central government has not increased the means-test financial threshold of £23,250 in line with inflation. The threshold-freeze remains for 2020/21, despite plans to increase the upper threshold [24]in April 2016, which was postponed to

[22] https://www.adass.org.uk/media/7973/no-embargo-adass-budget-survey-report.pdf [Accessed 22/09/20]
[23] https://www.adass.org.uk/media/7973/no-embargo-adass-budget-survey-report.pdf NB: the ADASS Budget Survey 2020 was based on 146 completed responses
[24] See Jarrett, T. (2015) Briefing Paper: Social care: how the postponed changes to paying for care, including the cap, would have worked (England) no. 07106 24 July 2015 [Accessed 18/09/20]

April 2020, and then not implemented (see [25]Local Authority Circular LAC (DHSC) (2020) published in March 2020). The threshold remains a bone of contention for many people with social care needs and their families, and we found no recent evidence to suggest that older people (in particular) have changed their attitudes about 'asset-based welfare' (Rowlingson, 2006). In other words, people are not keen to spend capital on social care causing reluctance to request support. They prefer to 'soldier on' without it. This attitude, combined with the much-publicized deterrent of 'deliberate deprivation of assets' may have resulted in a proportion of care needs not being met because they are not being expressed (Bradshaw, 1972). More research is needed to explore this topic.

Fourth, we would argue that the breakdown in spending per disability category (as outlined above) is disproportionate and possibly discriminatory. For example, whilst we know that 1 in 4 people [26]experience a mental health problem each year in England (with 1 in 6 experiencing e.g. anxiety or depression in any given week) total LA expenditure for mental health is comparatively low. This may reflect a group of people who are not accessing support. Similarly [27]estimates suggest that of the total number of people with a learning disability (around 2% of the UK population), only 23% of adults are identified (through GP registers) as having a learning disability in England, the remaining 77% an invisible majority. Further, LAs only have information of people with a learning disability 'known to their service'. This means that LAs may be making funding decisions based on flawed data sets. There is therefore an urgent need for investment into creating a readily available and reliable register of people with a learning disability in England.

[25] https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/872440/charging-for-care-and-support-local-authority-circular.pdf [Accessed 21/09/20]
[26] Mind mental health facts and statistics [online] https://www.mind.org.uk/information-support/types-of-mental-health-problems/statistics-and-facts-about-mental-health/how-common-are-mental-health-problems/#HowCommonAreMentalHealthProblems [Accessed 21/09/20]
[27] Public Health England (2015) Learning Disabilities Observatory, People with learning disabilities in England 2015: Main report https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/613182/PWLDIE_2015_main_report_NB090517.pdf [

## Proportions of people receiving care in light of LA reductions.

Given reductions in spending, it is unsurprising that fewer people appear to be receiving care. For example, for [28]2018/19, NHS digital (2020) reported that 841,850 adults were in receipt of LA-funded (long-term) social care which was concentrated primarily on those receiving residential/nursing home care, or domiciliary care, with 223,605 episodes of short-term care provided. This total marked a decline of 7% since 2015/16. Yet in the same year, [29]the Kings Fund reported that LAs received 1.9 million requests for social care from potential new recipients . Only a quarter (25%) of these were deemed eligible for support. The majority (1.4 million) requests were from older people, with 29% receiving formal care, and around 550,000 were from working-age adults of which 18% received support.

*Other factors impacting reduced care provision*

Budget cuts and the introduction of the Living Wage driving down the cost of care have not been the only factors operating to reduce social care provision. The government also encouraged an expanded private care market to develop. This cut care prices, allowing for the commissioning of cheaper care provision (e.g. supported living models as opposed to residential care homes). At the same time, it reduced care providers' ability to offer attractive wages (Hussein, 2017) – the Living Wage remains lower than the average shop assistant or cleaner's wage (King's Fund 2019). Low pay has resulted in lower recruitment and retention of care workers (Hatton, Emerson, Rivers, *et al*., 2001), especially among those with uncertain "zero hours" contracts (Ravalier, Fidalgo, Morton, and Russell 2017). An overstretched workforce capacity has been compounded by many care staff returning to their country of origin following the triggering of Brexit (Read and Fenge 2019).

The closure of care homes and contract hand-backs have been aggravated by day-service erosion (1 in 3 local authorities have already closed their day services

[28] NHS Digital Adult Social Care Activity and Finance Report England 2018-19 [online] https://digital.nhs.uk/data-and-information/publications/statistical/adult-social-care-activity-and-finance-report [Accessed 22/09/20]
[29] The King's Fund (2019) Key facts and figures about adult social care [online] https://www.kingsfund.org.uk/audio-video/key-facts-figures-adult-social-care [Accessed 22/09/20]

[[30]Unison 2019]) with few or no alternatives to mitigate these impacts. This all makes for a very fragile adult social care market and may have inadvertently led some councils to move towards more asset-based (e.g. Shared Lives and Wellbeing Teams) and self-help approaches for those with lesser needs. Sometimes seen as imaginative and conforming with key social care principles of personalisation and person-centredness (Hall, 2019), these approaches have at times been lauded as an ethical and practical solution to prevent or delay people from needing formal support (Hall, Needham and Hamblin 2020:322). However, little empirical evidence of their effectiveness in practice exists and in times of crisis (such as during the pandemic) it is unlikely that the third sector has capacity to support them in full.

***Comment:*** We would argue that there is much to be said for allowing individuals a greater say in the design and delivery of care needs. But this should be complementary to the full provision of their care and not, as can often be the case, a means of eroding the level or quality of the care they receive. Nevertheless, such approaches arguably also serve to curtail uptake of formal LA services thus helping with financial savings. They also open the door to re-interpreting 'low' needs as 'ineligible needs' – fitting with the idea that due to pending cuts, LAs have had to restrict their services to those with 'the greatest need'. Set against this background, eligibility as a means of allocating resources may be a useful economic construct though Culpitt's (1992:49) more skeptical appraisal is salutary:

"*there are insufficient resources available to meet all social needs, and assessment and interpretation of social need becomes a strategic activity, influenced by the vested interests and professional values of those who formulate welfare programmes*".

These various factors have contributed to an ever-growing body of unmet need, both in terms of what individuals are entitled to receive, what is necessary to meet their assessed needs and in the longer run what is sensible for society to provide today to avoid higher costs in the future. At the most basic level an individual enabled to stay in their own home rather than go into residential care is likely to have a higher quality of life and independence at a much lower cost to the state.

[30] https://www.unison.org.uk/at-work/local-government/key-issues/cuts-to-local-services/https://www.unison.org.uk/content/uploads/2016/11/24149_The_Damage_care_in_crisis_web.pdf [Accessed 22/09/20]

## Mapping 'unmet needs'

Understanding the nature and extent of unmet need for people with disabilities of working age (18-64) and older people (65+) is a critical social policy priority for any nation state, especially in the face of competing funding priorities (Vlachantoni, 2019:657). Unmet need is also a significant equality issue in terms of 'who gets what' social care related benefits and services (Liddiard, 2017:121). However the lack of nationally representative data, and an array of definitions of 'unmet need' make it difficult to assess. Definitions remain imprecise, complex, and inconstantly applied across studies (Diwan and Moriarty, 1995; Godfrey and Callaghan, 2000; Burchardt, Jones, and Obolenskaya 2018).

Overall, there is a lack of good-quality data pertaining to unmet need in relation to adult social care services – most studies we found (and excluded) related to medical and/or health care needs. Vlachantoni (2019:678) states that there is a dearth of empirical evidence of unmet need in the British context. This limits our understanding of the depth and breadth of the problem. There is also a scarcity of longitudinal studies to show changes over time. Previous quantitative research of 'unmet need' has tended to focus largely on older people. We found fewer studies pertaining to mental health, learning disabilities and physical or sensory disabilities. In some studies 'older people' is defined as those aged 60+ (e.g. Dunatchik *et al*., 2016) but in other studies, it is 65+ (e.g. Maplethorpe, Darton and Wittenbert, 2016). We provide a range of studies from across client groups that exemplify issues around unmet needs. These are set out below.

*Unmet needs in relation to age and gender*

Vlachantoni *et al*., (2011) explored data concerning the receipt of informal, state funded and formal paid support from three nationally representative data sets including the 2001/02 General Household Survey (GHS), the 2008 English Longitudinal Study of Ageing (ELSA) and the 2008/09 British Household Panel survey

to estimate unmet need among people aged 65+. These data sets measure need according to activities of daily living (ADLs) (e.g. bathing and dressing) and instrumental activities of daily living (IADLs) (e.g. preparing meals and budgeting) needed for independent living.

Vlachantoni *et al*., demonstrated significant unmet need regardless of which data set was used. They also found that older people experienced unmet needs in relation to certain ADLs. For example, 15-61% of the sample received no support with bathing, and 66% who found it difficult to dress in the morning, received no help. On the other hand, only 24% who had difficulty with housework or gardening reported not receiving any help with those tasks. Of those who did receive personal care, this was more likely to be provided by informal (unpaid) carers including relatives: 37% received informal support for bathing compared with 8% from formal state support and 3% from formal paid support. IADLs however were more likely to be provided by formal paid support (22% of older people who reported difficulty with shopping received formal support for this task).

By combining HSE data for 2011 and 2012 for those aged 65+, Whalley (2012) found gender differences in help for ADLs: with 30% of women compared to 22% of men receiving no support in the previous month. Similarly, 15% of women and 14% of men did not receive any help with even at least one IADL in the previous month. The activity with the highest levels of unmet need was getting up and down stairs (23% of women and 16% of men). Whalley also found that levels of unmet need increased with age: 32% of men and 43% of women aged 85+ had unmet need for help with getting up and down the stairs. Regional variations in unmet need were also found, with ADLs and IADLs greatest in the North West for both men and women (ranging from between (34% and 47%) compared to the South East (ranging from between 19% and 30%).

Other studies of older people tell roughly the same story of unmet need. For example, Maplethorpe, Darton, and Wittenberg's (2015) study based on HSE 2013/14 combined data found that almost a quarter (21%) of men and 29% of women aged 65+ had unmet need for at least one ADL, and 13% and 18% respectively had some unmet

need with at least one IADL in the previous month. Again, women were fairing badly compared to men; informal care was also significant. 82% of men and 75% of women received significant amounts of support from unpaid carers. Similarly, Brown and Morris (2018) examining unmet need for social care among adults aged 65+ using 2017 HSE data found that around a quarter of women (25%) and men (20%) had some unmet need with at least one ADL, and 15% of women and 12% of men had some unmet need with at least one IADL with unmet need, increasing with age for both ADLs and IADLS. Franklin (2015), using data from the ELSA reported that unmet need for older people had risen exponentially estimating that by 2012/13, 1 in 10 people aged over 50 had an unmet need. All of these studies indicate a consistent picture of unmet needs over time.

Dunatchik *et al*'s (2016) findings were even starker. Using two definitions of need (the LA (Care Act) definition, and a wider one that captured those with lower levels of need but who were not eligible for support) they found that 73% of older people (60+) measured using the LA (Care Act) definition and 58% of those under the wider definition had unmet needs.

More recently, Abdi *et al*., (2019) focused on the care and support needs of older people living at home with chronic conditions (including physical and mental disabilities) in the UK. Systematically reviewing 40 previous studies, they found that older adults (65+) experienced unmet social care needs including help with social activities and relationships, mobility, self-care and domestic tasks. Environmental factors that impinged on these needs being met included lack of professional advice on self-care strategies, poor communication and coordination of services, and lack of information on services and care pathways.

Studies comparing older people (65+) with younger (18-64) people indicated that whilst older people were more likely to have high needs, numerically more younger people needed help to remain independent. Burcharadt, Jones and Obonlenskaya (2018) combined data for 2012/13 and 2013/14 from the Family Resources Survey (FRS) of private households including those of working age (20-64) and older people

(65+). They defined ‘need’ broadly in terms of ‘high,’ ‘moderate’ and ‘low’ in relation to three questions: long-standing illness or condition, number of types of impairment, and the effect on day to day activities. They defined ‘unmet’ need using a high threshold - of those having either mild or moderate need, but receiving no formal or informal care. The majority of those with moderate needs reported no care (formal or informal) (76% of older people and 86% of working-age people) though a significantly higher proportion of older people than working-age people with moderate needs reported receiving at least some formal services (7.2% and 2.5% respectively). A higher proportion of older people than working-age people were also receiving at least some informal care (20.4% and 12.5% respectively).

As regards younger adults (18-64), Idriss, Allen and Alderwick (2020) suggest that unmet need is also rising. Using publicly available data from a range of sources, including the Adult Social Care Survey (ASCS), the Personal Social Services Survey of Adult Carers in England (SACE), the Family Resources Survey (FRS) and NHS Digital, they found that the needs of 18-64 year old people with learning disabilities, mental health problems and other social difficulties needs had increased from 14% in 2007/8 to 18% in 2017/18 (and 35% when combined with population growth).

In her more recent study, Vlachantoni (2019) uses Wave 7 data from the English Longitudinal Study of Ageing (ELSA) of almost 6,000 people aged 65+ living in private households in England. Once again, she found significant prevalence of unmet need (e.g. 55% of her sample experiencing difficulty with at least one ADL reported not getting any help) regardless of which types of ADL or IADL or mobility needs the person had. Being male and living alone were strong predictors of unmet need in relation to at least one ADL, and particularly so for personal tasks such as bathing. Being older (e.g. 85+) was also a predictor compared with those aged 65-74 and 74-84.

**Comment:** The above studies span the decade of austerity cuts to social care services. Vlachantoni’s findings show significantly higher prevalence rates of unmet need for older people compared to Maplethorpe, Darton and Wittenberg (2015). Whilst

Vlachantoni (2019:678) suggests that this difference 'almost certainly relates to diverse definitions of the population "at risk" of experiencing unmet need', she also states that it reflects the experience of unmet need in real terms. This demonstrates that despite various attempts of government to mitigate the deficits in social care provision, including the enactment of Care Act, unmet need remains a significant issue.

It is generally agreed that all ADLs and IADLs contribute to maintaining quality of life. But meeting needs such as bathing and dressing are highly significant for maintaining self-esteem and dignity, arguably more than help with, for instance, shopping. It is a cause for concern then, that many individuals in this study were not receiving help in this area. For those older people who were getting help with personal care, this was largely being provided by informal carers. The impact of purchasing regular personal care (e.g. through direct payments) on the relationship between formal carers and those they care for has been researched (e.g. Glendinning *et al.,* 2012). The psychological effects of providing personal care on informal carers have also been explored (e.g. Hansen, Slagsvold and Ingebretsen 2013). The impact of receiving help for personal care needs on older people, especially by informal carers however, has been less well documented and more research is needed in this area. Gender and age appear to be predictors of unmet need (those aged 85+ being particularly vulnerable) though more qualitative analysis of how this is experienced by individuals is needed, especially in the light of study findings that specifically compare older and younger people with disabilities as described below.

*Unmet needs in relation to disability*

Given the scarcity of empirical evidence of unmet need for social care in England, it is unsurprising that studies relating to particular disabilities for adults were difficult to find. Miranda-Castillo *et al*., (2013) in their study of people with dementia across three counties of England used a number of instruments to cover 124 areas of needs encapsulating social, psychological, physical and environmental needs. Between 2005 and 2007, they interviewed 152 people with dementia who were 60+ and living

in their own homes. They also interviewed 128 informal carers. They found that over half the sample (50.7%) of people with dementia had unmet needs for daytime activities, company (39.5%), and help for psychological distress (30.9%). They also found that higher unmet needs were associated with poor community social interaction, having younger carers, and/or carers who had high anxiety.

Using more qualitative methods, Górska *et al.* (2013) conducted semi-structured narrative interviews with 12 people who had dementia (average age 84, range 77-93) and 19 carers (average age 65, range 40-84). Apart from the need for early diagnosis delivered through a comprehensive assessment package, the participants reported unmet social care needs relating to post-diagnostic support, continuity of care and access to non-pharmacological interventions to support identity and social engagement. Older people with dementia are likely to have higher levels of social care need - not receiving support with these may be regarded as a kind of double-jeopardy both for themselves and for those who care for them.

Docherty and Thornicroft (2015:1) argued that since the start of austerity in 2008, anecdotal reports have suggested that mental health services in England have been cut, leading to unmet need. Yet few studies exist to test this proposition. As part of their review of official, research and grey literature to map the situation, they found that across England social service cuts had led to a decrease of 48% in the number of people with mental health difficulties receiving care (compared to only 32% of NHS expenditure reductions in some local areas). They note that such reductions in mental health services have not been matched to those of physical health services. This, they argue is also counter-intuitive to 'parity of esteem' of health and social care (though we could not find any relevant studies to corroborate this assertion).

Lambri *et al*. (2012) interviewed a random sample of 110 participants with severe mental illness (SMI) living in a range of housing accommodation including rehabilitation units, and high, medium and low supported housing in Haringey, England. They also interviewed 110 keyworkers. Their cross-sectional study used among other instruments, the Camberwell Assessment of Need Research (CAN-R) which assesses needs for support over the last month, and the Lancashire Quality-of-

Life profile. They found that residents' housing needs were generally met. But social and quality of life needs - especially for those living in low-supported housing - tended to be overlooked and not met by services.

Some studies report on specific unmet needs such as for accessible housing (e.g. Satsangi *et al*., 2018), and Bodsworth *et al*. (2011) used a self-report survey (adapted for each person's particular need) to examine psychological distress and unmet need among 539 people belonging to Deafblind UK from across England and Wales. They found high levels of unmet need particularly practical, domestic and social support; over a quarter (26.9%, *n* = 504) reported that they received no formal support but wanted it. We found very few studies

In their mixed-methods analysis of 160 care-recipients of social care and 189 carers in both 2013 and 2015 in England, Brimblecombe *et al.*, (2017) found perceived unmet needs at both time-points. In 2013, 44% of care-recipients reported unmet need for services (no data exist for 2015) and the majority of carers (72% in 2019 and 69% in 2015) reported that the person they cared for needed more services. Amongst other things, perceived unmet needs were linked to structural issues of formal care provision (similar to the findings of Abdi *et al.* [2019]). This included unreliability, lack of continuity of care, and too-short care visits. Informal carers also reported having to take up the slack when formal care could not be 'trusted'. Similar findings for older carers of older people with learning disabilities were reported by Forrester-Jones (2019).

*Learning disabilities*

In their study of 150 people with a learning disability in England, Forrester-Jones *et al*. (2020) found that during the period of austerity, the majority (42%) had lost care, 14% had experienced changed care, and care had remained the same for 36% over the period of austerity. Only 7% said their care had improved. They concluded that social care needs were clearly not being met, with individuals engaged in fewer activities and experiencing poorer self-esteem and quality of life than those who had not lost care.

Participants had also experienced a loss of independence and an increased reliance on their families/ third sector for support. They were also anxious about their futures and feared losing social care funding and support.

Other studies around learning disabilities similarly show that despite considerable policy and research in the interim decades, the needs most important to the wellbeing of many disabled people such as relationships, effective support and meaningful community engagement (Bhardwaj, Forrester-Jones and Murphy, 2017) and employment (Forrester-Jones, Gore and Melling, 2010; Gore, Forrester-Jones and Young, 2014) and support to practice their faith, is often unmet (Sango and Forrester-Jones, 2017).

**Comment:** we did not find any empirical studies pertaining to unmet needs specific to people from Black, Asian or Minority Ethnic (BAME) backgrounds living in England. Willis et al., (2016) measured satisfaction of social care services with 82 service users and family carers from white British and South Asian backgrounds in Hampshire, Portsmouth and Southampton. They found that the majority of their sample reported a positive satisfaction rating when using a questionnaire, but at interview, their narratives gave a more negative perspective. However, this study did not directly measure unmet needs. The majority of participants in most studies mapping unmet needs [e.g. Brimblecombe *et al.*, (2017) and Forrester-Jones *et al.*, (2020)] were White British, Irish or Other White). This indicates a major gap in evidence of the particular barriers people with disabilities from BAME background face in meeting their need for social care. Likewise, the unmet needs of LGBT older adults and adults with disabilities in England have not been mapped sufficiently. If their experiences equate to those of their counterparts in America (see for example, Brennan-Ing *et al.*, 2014 whose study sample included a third from BAME backgrounds), they will face additional difficulties getting their needs met, including discrimination from service providers. There is therefore a need for more studies exploring unmet need in relation to intersectionality.

## The problem of defining and measuring 'unmet need'.

Our review of the literature concerning need and unmet need is not exhaustive but presents the rather bleak situation people with disabilities are in. However, the range of approaches, methodologies and analyses employed to measure unmet need described in the available studies we have presented above also shows that need and unmet need as concepts remain complex, imprecise and therefore 'fuzzy'. Dunatchik, Icardi, Roberts and Blake (2016:13) argue that this is because needs are met in various ways (e.g. informal unpaid care, self-funded support, LA funded formal care, digital adaptations). This means that we do not have a comprehensive picture of unmet need across disability or across England. The problems of using particular conceptualizations and approaches for measuring unmet need are outlined below:

*Functional-normative approach*

The functional-normative approach measures the extent to which a person can perform 'normal' self-care activities for daily living (ADLs) (as well as instrumental daily activities (IADLs) to enable independent living (e.g. preparing meals and budgeting). If they are unable to carry out these tasks independently, then they would be regarded as having a 'need' for support to help them do so. Unmet needs are defined as those tasks the person is unable to do without support, but does not get support.

This definition and approach appears to be generally used to measure the prevalence of needs and unmet needs in England – e.g. the Health Survey for England (HSE) Reports (Maplethorpe *et al*., 2015; Brown, Morris, and Neave, 2018), and studies employing secondary analysis on data from the English Longitudinal Study of Ageing (ELSA), the General Household Survey (GHS), and the British Household Survey (BHPS) (see Vlachantoni et al 2011; Lloyd and Ross, 2014; Dunatchik *et al*., 2016).

***Comment:*** Whilst this approach offers an objective measure of need/unmet need, each survey assumes a different methodology for asking about people's needs (Dunatchik *et al*., 2016). For example, the ELSA survey presents people with a list of

activities and asks them to pick out which ones they have difficulties with. On the other hand, the HSE presents a series of activities to individuals who are asked to report how difficult they find each of them (Dunatchik, 2016:26). Arguably, these subtle differences can lead to variable outcomes.

Furthermore, survey construction, including the choice and number of activities incorporated within it is pre-set, as are the thresholds for needing support. For example, HSE data of unmet need is based on respondents aged 65+ reporting difficulties with at least one ADL (or IADL) for which they have not received help in the last month. Care Act eligibility criteria (see The Care and Support (Eligibility criteria) Regulations 2014) however, is based on a person's inability to achieve two or more specified outcomes for daily living resulting in significant impact on their well-being (HSE helpfully indicates these differences in the Table 1 below).

**Table 1 Comparisons in defining need used for measuring unmet need**

| **Care Act** | **ADL** | **IADL** |
|---|---|---|
| Managing and maintaining nutrition. | Eating, including cutting up food. | Shopping for food. |
| Maintaining personal hygiene. | Having a bath or shower. Washing face and hands. | Doing routine housework or laundry. |
| Managing toilet needs. Being appropriately clothed. | Using the toilet.<br>Dressing and undressing. | Getting out of the house. |
| Being able to make use of [their] home safely. | Getting up and down stairs. Getting around indoors. Getting in or out of bed. | |
| Maintaining a habitable home environment. | | Doing routine housework or laundry |
| Making use of necessary facilities or services in the local community, including public transport and recreational facilities or services. | | Getting out of the house |

*Source: Table B: Comparison between national eligibility criteria, ADLs and IADLs Health Survey for England 2017: Adult Social Care page 8*

Dunatchik *et al*., (2016) also argue that the ADL and IADL based approach does not involve any service-user evaluation as to whether their needs are met, or whether the 'help' received is appropriate or helpful. There is also an inherent assumption that once support is in place, the need is 'met' - regardless of the quality of support provided or who provides the support (formal, informal or a mixture of both). Attempting to redress some of these issues, they investigated unmet need for people aged 60+ using two definitions: an LA (Care Act 2014) (as described previously).

All of the above definitions of need/unmet need may be regarded as following a 'deficit' approach (Glasby *et al*., 2013). They focus on what people can't do. Hall *et al.,* (2020: 323) argues that this encourages passivity and dependence and fails to recognise the assets that people have and how they can make a positive contribution to society. A more asset-based approach has become more popular, supported by the principles of the Care Act and the associated focus on subjective well-being but as argued above, there are limits to its functionality and effectiveness. Conceptualising and understanding need and unmet need therefore remain problematic - we briefly outline some ideas around these concepts and their relationship with eligibility.

*Conceptualising need and unmet need*

Most commentators would agree that the concept of human need is central to social protection policy and resource allocation. While some scholars have argued that human needs are subjective (Armstrong, 1982) and therefore outside the scope of social policy (Culyer *et al*., 1971) Maslow's (1943) famous hierarchical model deemed certain 'basic needs' (e.g. physiological and safety) as necessary in order for self-actualisation to be realised. Maslow's model has had renewed interest of late, particularly in relation to measuring unmet needs of older people and their carers (see Schölzel-Dorenbos et al., 2010). Alternatively, Bradshaw's (1972) taxonomy distinguished between normative need – set and expressed by professionals or 'experts' as to what 'the norm' of a society is (e.g. benefit level's, or residential care home standards), felt or subjective need from the perspective of those who have it, expressed need (what people say they need) and comparative need (in comparison

with others who are not in need). The comparative need relates to levels of services and standards achieved by other groups or communities of people. Relating this to social care, we can argue that if an individual or group uses a care service less than another person, or the service they use is not adequate compared to another person(s) service, then that individual(s) is in need. The principle for comparative need is the basis for the idea of 'territorial justice' or as it is framed now 'levelling up' or 'rebalancing' of services i.e. that all areas with similar populations should have the same levels of services, standards, and opportunities. There is little evidence of strategic planning to level up social care - either by an equalization strategy by reducing the supply of needed resources to the relatively less needy, or a strategy of maximizing resources, by increasing the supply of needed resources to the relatively more needy – or a mixture of both.

Finally, Doyal and Gough (1984) and others distinguish between 'wants' and 'needs,' with 'wants' described as a state of mind and (Campbell, 1998) needs deemed necessary for the avoidance of harm. For them, needs (and therefore unmet needs) are objective and measurable and can be used to make decisions about resource distribution.

*Unmet need*

The question of whether 'unmet need' exists and to what extent, is both philosophical and political and has empirical and normative components. Empirically, research can provide evidence based on measures of how far people's needs are being met. The normative component relates to the question of 'what are human needs?' since clearly the extent of unmet needs depends on how human needs are defined. From its inception, the UK welfare state, based on social democratic principles generally developed a collective provision to meet people's needs for economic security, housing, work, education and health care paid mainly through taxation. Greater equality was a key goal and during the period from the 1940s to the 1970s, the UK experienced a reduction in the gap between rich and poor. Entitlement to state welfare was guaranteed by the social rights of citizenship. However, towards the end of the twentieth century, successive governments driven by neoliberal ideology launched an alternative philosophical approach - one that believes that human needs are best met

through the private realms of markets or families. This has led to a steady retrenchment of state provision of welfare with a smaller 'safety-net' of protection and tighter criteria for 'eligibility' of support for what are regarded as 'legitimate' needs.

Certainly for those who need support to enable them to participate in everyday living, being eligible or ineligible for social care is highly significant practically, but also personally, psychologically and socially. In their study of the impact of austerity measures on the lives of people with learning disabilities, Forrester-Jones *et al.,* (2020) found that the fear of becoming less eligible for support drove some individuals to question the purpose of gaining independent living skills.

Eligibility may also embody personal constructs about 'self' beyond access to services to meet need. For example, the term 'need' brings stigma with it; many people with disabilities having to accept, over time, that they belong to a stigmatised social category that 'needs' other people to validate them and their contribution to society. Self-awareness and acceptance of social group belonging is regarded as necessary to realistically formulate one's self-concept (Monteleone and Forrester-Jones, 2017) as well as for developing coping mechanisms when socially interacting with wider society (Szivos & Griffiths, 1990). To suddenly be deemed as less eligible or ineligible for social care, on the basis of having needs that are no longer defined as severe enough to access public social care may lead to perceptions that others view them as 'less deserving' of state support when in reality, their struggles with daily living remain the same. What this experience means to individual's personhood is yet to be tapped but one which is significant since embodiment of a particular societal status (particularly if it is stigmatised) can affect individual's wellbeing (Monteleone & Forrester-Jones, 2017).

**Next steps**

We would hope that this initial report will provide a robust foundation for a systematic study of unmet needs and decisions are made to address them across different population segments and regions.

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## Annex 1. The Care Act 2014

### *Who can get social care and how do they get it?*

Under the Care Act 2014, the LA has a legal responsibility to assess a person's needs (via a needs assessment) if it appears that the person is in need of care and support. Arguably this could include anyone in the community who appears to be in need of support. [31]To be lawful, the needs assessment must consider how best to maintain or improve the person's 'well-being'. Outcomes of well-being include the following: dignity; mental and emotional health; protection from abuse and neglect; autonomy and choice over their day- to-day life; ability to participate in education, work, training or recreation; social and economic well-being; social and family relationships; the suitability of their living accommodation; and their contribution to society.

### *An asset-based approach*

Underpinning the Care Act is an 'asset-based' principles. Defining and assessing needs using this approach starts with what the person 'can do', then moving to how support can maintain these skills and prevent dependency. This moves away from the 'deficit' style of charting what people are unable to do. However, in a landscape of increased rationing of services, Hall *et al*., (2020:323) argue that assessments rapidly end up being more about gatekeeping of resources, than providing support. They also contend that empirical evidence of success of the asset-approach is lacking; suggesting that LAs may find it too experimental to try, especially at a time when they are strapped for resources to keep basic care services afloat.

### *Needs assessments under the Care Act 2014*

[31] The following section is paraphrased from Forrester-Jones (2019) Legal Considerations, Chapter 4 p.41-52 In Understanding and Responding to Behaviour that Challenges in Intellectual Disabilities (2nd Edition) Baker, P. and Osgood, T. (Eds) West Sussex, Pavillion

Needs assessment must be completed within a 'reasonable time frame' (around four to six weeks from when the request was made). They must also be carried out by a competent and trained assessor (e.g. a social worker). However, in her study of older carers Forrester-Jones (2019) found of poor knowledge about learning disabilities amongst some staff, including those carrying out needs assessments, poor knowledge about particular conditions was lacking in some of 'gatekeepers' including needs assessors could be generic rather than specific knowledge of particular disabilities putting into question the process and outcome of the assessments.

Assessments should also involve the focal person, as well as any other relevant carers (including any family, friends, neighbours and advocates) in every aspect of it, with the underlying assumption that the person is the best judge their own abilities, goals and needs to support these. If needed, an independent advocate should be involved and if the focal person has 'substantial difficulty' in participating in their own assessment and care-plan, an 'appropriate individual' (e.g. a relative) or independent advocate should be asked about the person's needs (including communication requirements). An expert opinion from a psychologist, psychiatrist, or specialist behaviour nurse may also be required to fully understand the person's needs (Department of Health and Social Care (2018)). In the case of a person displaying challenging behaviour, a 'functional assessment' should be part of the assessment process so that the behaviour can be analysed; its antecedent (what triggers the behaviour) identified; and its purpose understood. A positive-behaviour support plan can form part of the subsequent overall care planning process.

The local authority (LA) has a duty to meet all of the person's 'eligible needs' identified in the assessment. Despite the asset principles of the Care Act, [32]the Care and Support (Eligibility Criteria) Regulations 2015 no. 313 para 2 s(2) define 'eligible needs' as those tasks a person is 'unable' to do on their own if unsupported to or being related to a physical or mental impairment or illness – thereby reverting to a 'deficit'

[32] http://www.legislation.gov.uk/uksi/2015/313/pdfs/uksi_20150313_en.pdf [Accessed 30/09/19]

model. To be eligible for support, the person has to have two or more of the following 'eligible needs':

- Managing and maintaining nutrition;
- Maintaining personal hygiene;
- Managing toilet needs;
- Being appropriately clothed;
- Being able to make use of the adult's home safe;
- Maintaining a habitable home environment;
- Developing and maintaining family or other personal relationships;
- Accessing and engaging in work, training, education or volunteering;
- Making use of necessary facilities or services in the local community including public transport, and recreational facilities or services;
- Carrying out any caring responsibilities the adult has for a child.

***Meeting a person's needs***

The LA must meet the person's identified needs by using a person-centred and person-led 'care and support plan' or a 'positive behavioural support plan'. The individual and their family/carers should agree the plan and it should be reviewed at least annually. If the individual or their family do not think the support plan will improve their well-being, they can complain to the LA, or if necessary, the local government ombudsman. Alternatively, legal advice can be sought.

The LA will carry out a financial 'eligibility' assessment to determine whether or not the person needs financial assistance to pay for their care. Unlike NHS services, social care is means-tested and if the person has assets (including capital including savings and property or income such as an occupational pension) of more than

[33]£23,250, they will have to pay for their own care. If the individual is not financially eligible, the LA should still arrange the care.

If the individual has additional health and housing needs, the LA must notify the NHS or housing authority who will carry out their own assessments. The LA, NHS and other relevant agencies have a legal duty under the NHS Act (2006) and the Care Act (2014) to co-operate with one another to ensure that the person's needs are met. For people with 'a primary health need', e.g. complex psychological or behavioural difficulties that require specialist care, or complex medication or feeding needs etc., they may be eligible for NHS 'continuing healthcare'. Unlike social care, this type of medical care will be free regardless of the person's financial circumstances and it can also be paid as a personal health budget (the individual agrees with the NHS how the money will be spent) or as a direct payment. A nurse assessor using a 'decision support tool' will assess on a continuum from 'no needs' to 'priority needs' a number of medical need 'domains' (see Department of Health and Social Care (2018) p. 6 para 20, Fig.1). If the person does not get NHS continuing healthcare, the NHS and the LA may agree to 'joint funding' the care. If the LA or NHS do not meet the individual's needs according to the support plan (including providing a cheaper service which is less beneficial to the person's well-being) they are acting unlawfully and families can make a formal or legal complaint.

[33] Current threshold as of September 2020

## Annex 2. Method

This never set out to be, nor is it, a systematic review. Rather, by drawing from a number of sources it attempts to provide an academic lens through which we can gain a better understanding of unmet needs in relation to social care with a view to informing better decision making.

In order to draw from relevant material, we conducted an initial google-scholar search to explore best-fit search terminology. This was followed by a period of testing of a number of broad domains and keywords in various relevant search engines until key-words were decided upon. Using the broad domains of 'unmet needs' and 'disability' key words were searched alongside each other. We also searched the Cochrane Library, he EPPI-Centre Knowledge Library and Cambell Systematic Reviews but found no reviews specifically on the topic of unmet social care needs of adults with disabilities.

*Eligibility criteria and search strategy*

*Inclusion criteria*

To be included, articles and reports must have addressed the topic of 'unmet need' in relation to people with disabilities. These encompassed learning disabilities, people with mental illness, older people and people with physical disabilities. We hoped that this would allow us to reveal the voices of end-users and multi-disciplinary groups. The viewpoint of non-frontline workers (e.g. policymakers, social care managers) was also included. Studies were included if they were empirical peer-reviewed research articles using qualitative, quantitative, and/or mixed method approaches, as well as grey literature including reports published between January 2008 and September 2017. Earlier publications were excluded, since 2008 is the year that is generally accepted as signifying the beginning of the global economic crisis. No gender or demographic restrictions were imposed on the population with disabilities. Limiters were English and adults, as the aim was to evaluate how austerity has impacted both working age and older adults.

*Exclusion criteria*

Given that the methodological validity of unpublished studies (a sub-category of grey literature) may be difficult to evaluate, we excluded these, along with any that focused on medical health, transitions from youth to adulthood or prison populations.

*Screening process*

Electronic searches of the search engines Scopus, International Bibliography of the Social Sciences (IBSS), APA PsychNet, JSTOR, Web of Science, and Social Policy and Practice were carried out in September 2020. Whilst we did not wish to exclude any potentially relevant articles, we found that a substantial number of papers were irrelevant because autism, learning disabilities and old are highly-utilised terms within the topic range.

Our searches resulted in a total of 447 relevant hits by title and abstract. Once these had been sifted for duplicates and irrelevance, as well as methodological flaws and weaknesses, we agreed on the papers and articles that would be most relevant for setting out the context of unmet need for social care in England. These are presented throughout the report.